

# Wisconsin's Older Dementia Population

A summary of data about older persons with dementia

Updated 9/2004

This report profiles Wisconsin's older residents with dementia. Information is available about two groups: Those who live in the community and receive publicly-funded long term support services<sup>1</sup>, and those who live in nursing homes. Unfortunately, we know little about the majority of the dementia population: people who live in the community and are not in the State's long term support system. However, the available information can help us plan outreach and services for all older Wisconsin residents with dementia.

## Demographics

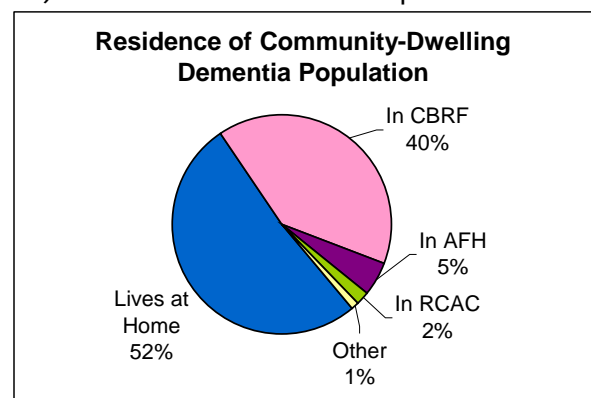
According to the 2000 Census, 702,553 people age 65 and older live in Wisconsin. When a widely-used estimation procedure is applied to the state's noninstitutional population, it suggests that an estimated 97,548 persons age 65 and older have dementia and live in the community<sup>2</sup>. Nursing home reports show that another 18,776 people age 65 and older have dementia and live in Wisconsin nursing homes. Taken together, these two numbers indicate an estimated total of 116,324 people age 65 and older with dementia in Wisconsin.

Alzheimer's disease and other dementias occur more frequently with advancing age. Among noninstitutional, community dwelling persons age 85 and older, experts estimate that 47% experience some level of dementia. In Wisconsin, this translates to approximately 44,944<sup>3</sup> individuals (there are a total of 95,625 Wisconsin residents age 85 and older). An additional 10,718 nursing home residents with dementia are 85 and older, for a total of 55,662 persons. These "oldest old" persons make up nearly half (48%) of all older persons with dementia, while in general people 85 and older comprise just 14% of all older people.

## The Community-Dwelling Population

In 2003, a total of 919 older people with dementia were enrolled in Wisconsin's community long term support services through the Community Options Program or one of its Medicaid waiver programs, and are included in the state's Human Services Reporting System (HSRS). Of these, 475 (52%) lived at home, 370 (40%) lived in a community-based residential facility (CBRF), 45 (about 5%) lived in Adult Family Homes, and 19 (2%) lived in Residential Care Apartment Complexes (RCACs). The remainder had other residential arrangements. Within these settings, 307 (33%) lived with family members, 418 (46%) lived with others who were not family members, and 194 (21%) lived alone. A total of 205 were married (22% of those for whom marital status was recorded).

Most (about 96%) had natural supports, sometimes from more than one source: 557 from their children, 162 from spouses, 64 from a guardian, and 96 from another relative

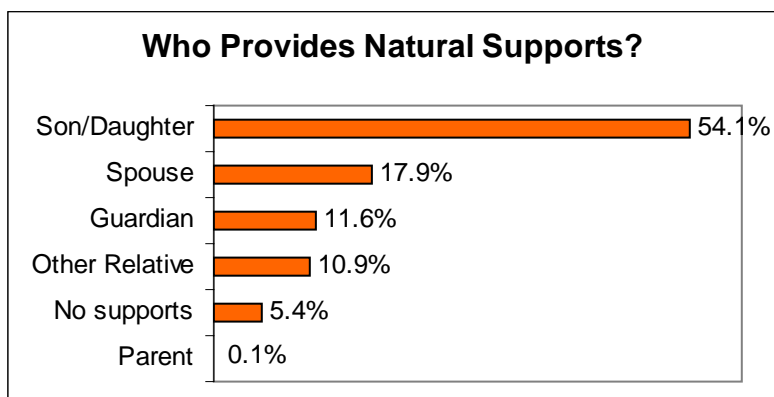


<sup>1</sup> These include the Community Options Program (COP) and related Medicaid waiver programs (COP-W and CIP-II).

<sup>2</sup> This estimate is based on Evans, et.al., "Prevalence of Alzheimer's Disease in a Community Population of Older Persons." Journal of the American Medical Association 262(18), 1989. Recommended dementia prevalence rates are applied to the noninstitutional 65+ population only (not nursing home residents).

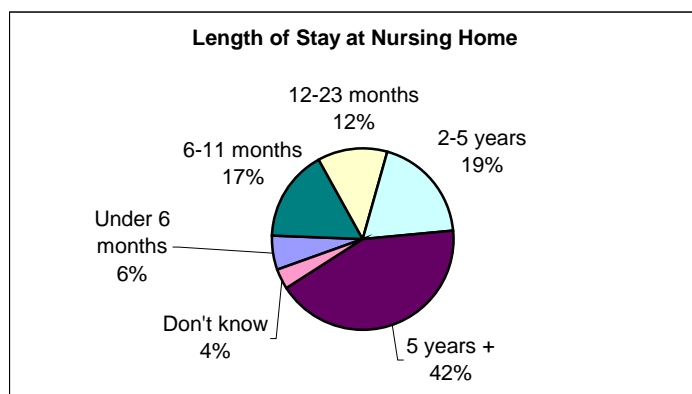
<sup>3</sup> For the 85+ population, the dementia estimate is applied to the total 85+ population because Census 2000 data is not yet available to distinguish the institutionalized population in this age group.

(including one parent). Forty individuals had no natural supports. Court orders governed 148 of these cases, including 65 cases in Dane County. Excluding Dane, about 9% of cases statewide fall under court orders. Ninety persons (about 10%) were relocated to the community from a nursing home.



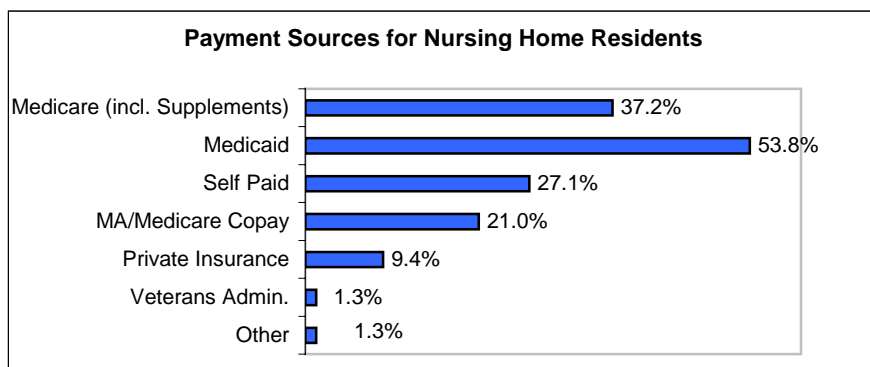
## The Skilled Nursing Facility Population

According to the Minimum Data Set, collected from nursing homes by the State of Wisconsin to meet a federal mandate, a total of 35,096 people age 65 and older lived in skilled nursing facilities at the end of 2000, and 18,063 (51.5%) of them had Alzheimer's disease or another dementia. A large majority (74%) were women, and most (63%) were widowed, although another 22% were married (almost the same proportion as in the HSRS client population discussed above). In the nursing home population, well over half of older residents (57%) are age 85 and older (compared to an estimated 48% of the state's older dementia population as a whole).



The largest share (42%) of nursing home residents with dementia have been living at their current facilities for five years or more. About 23% have been in residence less than one year, and another 12% have resided there between one year and 23 months. One-fifth (19%) have been at their facilities for 2-5 years (no information is available on the length of stay of 4% of nursing home residents with dementia).

Most persons with dementia living in nursing homes are supported in part by Medicaid (54%) or Medicare (37%, including those who receive supplements A or B). Altogether, 27% pay for part of their care themselves (or with family help), and 21% make a Medicaid or Medicare copayment. Nine percent are funded through private insurance. A small number receive funding from the Veteran's Administration (about 1%) and about 1% have some other source of funds. Since many residents use more than one source of payment, these percentages do not total 100%.

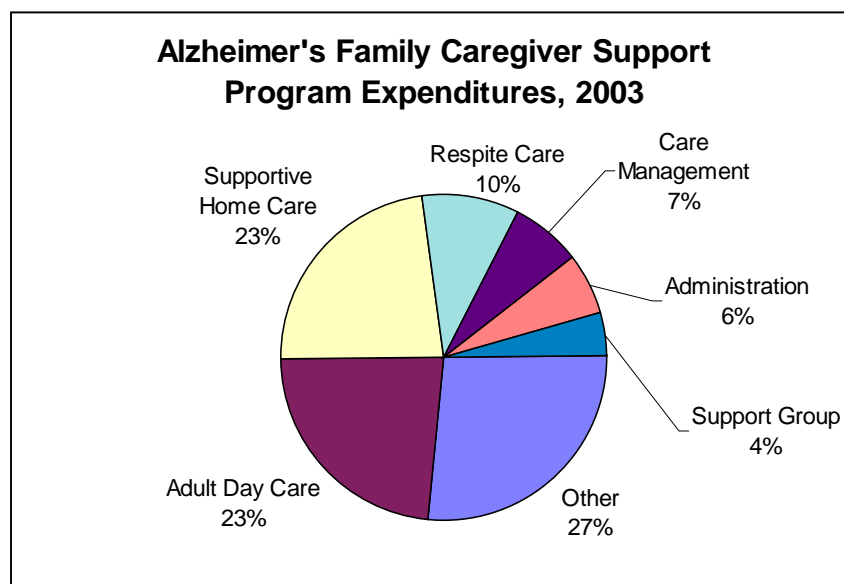


Of persons with dementia who were living in nursing homes at the end of 2000, about 10% indicated a wish to return to the community. A little over 5% had a support person who was positive toward discharge to a community residential setting. There had been little or no change in the condition or the care needs of a large majority (86%), although about 11% were reported to have experienced a deterioration in their condition in the past 90 days, requiring increased supports. The condition of about 3% had improved.

## **Alzheimer's Family Caregiver Support Program**

Across Wisconsin during 2003, a total of 977 individuals were enrolled in the Alzheimer's Family Caregiver Support Program (AFCSP). This program provides assistance and services up to a maximum of \$4,000 per year to enable persons with Alzheimer's disease and other dementias to remain in the community. In addition, 8,541 individuals were "indirectly served," receiving caregiver education, resource information, or other services. Households eligible for services through this program have incomes below \$40,000 and are required to share in the cost based on a sliding fee scale. Typically, participants are just over the income level for other publicly supported programs and their caregivers rely on this program to help with the cost of caring for a person with Alzheimer's disease.

The AFCSP provides funding for a range of services including supportive home care, adult day care, respite care, case management, and caregiver support groups. Over time, the share of expenditures providing respite care has decreased while the proportion spent on supportive home care and case management has increased (case management was added as a reporting category in 1994). As the chart shows, the largest share of funding in 2003 covered adult day care and supportive home care services, at 23% of all expenditures each.



### **Sources:**

U.S. Bureau of the Census, Census 2000, Summary File 1.

Wisconsin Human Services Reporting System, 2003. Tables provided by Misty Johnson, DHFS Bureau of Aging and Long Term Care Resources.

Wisconsin Minimum Data Set, December 31, 2000. Tables provided by Anthony Reeves, DHFS Bureau of Quality Assurance.

Data on Alzheimer's Family Caregiver Support Program for 2003 provided by Susan Veleke, DHFS Bureau of Aging and Long Term Care Resources.

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